



106TH CONGRESS
1ST SESSION

S. 628

To amend titles XVIII and XIX of the Social Security Act to expand and clarify the requirements regarding advance directives in order to ensure that an individual's health care decisions are complied with, and for other purposes.

IN THE SENATE OF THE UNITED STATES

MARCH 16, 1999

Mr. ROCKEFELLER (for himself, Ms. COLLINS, Mr. COCHRAN, Mr. CONRAD, Mr. WYDEN, and Mr. JEFFORDS) introduced the following bill; which was read twice and referred to the Committee on Finance

A BILL

To amend titles XVIII and XIX of the Social Security Act to expand and clarify the requirements regarding advance directives in order to ensure that an individual's health care decisions are complied with, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE; TABLE OF CONTENTS.**

4 (a) SHORT TITLE.—This Act may be cited as the
5 “Advance Planning and Compassionate Care Act of
6 1999”.

1 (b) TABLE OF CONTENTS.—The table of contents of
2 this Act is as follows:

Sec. 1. Short title; table of contents.

Sec. 2. Development of standards to assess end-of-life care.

Sec. 3. Study and recommendations to Congress on issues relating to advance
directive expansion.

Sec. 4. Study and legislative proposal to Congress.

Sec. 5. Expansion of advance directives.

Sec. 6. National information hotline for end-of-life decisionmaking.

Sec. 7. Evaluation of and demonstration projects for innovative and new ap-
proaches to end-of-life care for medicare beneficiaries.

Sec. 8. Medicare coverage of self-administered medication for certain patients
with chronic pain.

3 **SEC. 2. DEVELOPMENT OF STANDARDS TO ASSESS END-OF-**
4 **LIFE CARE.**

5 (a) IN GENERAL.—The Secretary of Health and
6 Human Services, acting through the Administrator of the
7 Health Care Financing Administration, the Director of
8 the National Institutes of Health, and the Administrator
9 of the Agency for Health Care Policy and Research, shall
10 develop outcome standards and measures to evaluate the
11 performance of health care programs and projects that
12 provide end-of-life care to individuals and the quality of
13 such care.

14 (b) REPORT TO CONGRESS.—Not later than 2 years
15 after the date of enactment of this Act, the Secretary of
16 Health and Human Services shall submit a report to Con-
17 gress concerning the outcome standards and measures de-
18 veloped under subsection (a).

1 **SEC. 3. STUDY AND RECOMMENDATIONS TO CONGRESS ON**
2 **ISSUES RELATING TO ADVANCE DIRECTIVE**
3 **EXPANSION.**

4 (a) STUDY.—The Secretary of Health and Human
5 Services shall conduct a thorough study regarding the im-
6 plementation of the amendments made by section 5.

7 (b) REPORT.—Not later than 18 months after the
8 date of enactment of this Act, the Secretary of Health and
9 Human Services shall submit a report to Congress that
10 contains a detailed statement of the findings and conclu-
11 sions of the Secretary regarding the study conducted pur-
12 suant to subsection (a), together with the Secretary's rec-
13 ommendations for such legislation and administrative ac-
14 tions as the Secretary considers appropriate.

15 **SEC. 4. STUDY AND LEGISLATIVE PROPOSAL TO CONGRESS.**

16 (a) STUDY.—

17 (1) IN GENERAL.—The Secretary of Health and
18 Human Services shall conduct a thorough study of
19 all matters relating to the creation of a national uni-
20 form policy on advance directives for individuals re-
21 ceiving items and services under titles XVIII and
22 XIX of the Social Security Act (42 U.S.C. 1395 et
23 seq.; 1396 et seq.).

24 (2) MATTERS STUDIED.—The matters studied
25 by the Secretary of Health and Human Services

1 under paragraph (1) shall include issues
2 concerning—

3 (A) the election or refusal of life-sustaining
4 treatment;

5 (B) the provision of adequate palliative
6 care including pain management;

7 (C) the portability of advance directives,
8 including the cases involving the transfer of an
9 individual from 1 health care setting to another;

10 (D) immunity for health care providers
11 that follow the instructions in an individual's
12 advance directive;

13 (E) exemptions for health care providers
14 from following the instructions in an individ-
15 ual's advance directive;

16 (F) conditions under which an advance di-
17 rective is operative;

18 (G) revocation of an advance directive by
19 an individual;

20 (H) the criteria for determining that an in-
21 dividual is in terminal status; and

22 (I) surrogate decision making regarding
23 end of life care.

24 (b) REPORT TO CONGRESS.—Not later than 18
25 months after the date of enactment of this Act, the Sec-

1 retary of Health and Human Services shall submit a re-
2 port to Congress that contains a detailed description of
3 the results of the study conducted pursuant to subsection
4 (a).

5 (c) CONSULTATION.—In conducting the study and
6 developing the report under this section, the Secretary of
7 Health and Human Services shall consult with physicians
8 and other health care provider groups, consumer groups,
9 the Uniform Law Commissioners, and other interested
10 parties.

11 **SEC. 5. EXPANSION OF ADVANCE DIRECTIVES.**

12 (a) MEDICARE.—Section 1866(f) of the Social Secu-
13 rity Act (42 U.S.C. 1395cc(f)) is amended—

14 (1) in paragraph (1)—

15 (A) in subparagraph (B), by inserting
16 “and if presented by the individual, to include
17 the content of such advance directive in a
18 prominent part of such record” before the semi-
19 colon;

20 (B) in subparagraph (D), by striking
21 “and” at the end;

22 (C) in subparagraph (E), by striking the
23 period and inserting “; and”; and

24 (D) by inserting after subparagraph (E)
25 the following:

1 “(F) to provide each individual with the oppor-
2 tunity to discuss issues relating to the information
3 provided to that individual pursuant to subpara-
4 graph (A) with an appropriately trained profes-
5 sional.”; and

6 (2) by adding at the end the following:

7 “(5)(A) An advance directive validly executed outside
8 of the State in which such advance directive is presented
9 by an adult individual to a provider of services, a
10 Medicare+Choice organization, or a prepaid or eligible or-
11 ganization shall be given the same effect by that provider
12 or organization as an advance directive validly executed
13 under the law of the State in which it is presented would
14 be given effect.

15 “(B) Nothing in this paragraph shall be construed
16 to authorize the administration, withholding, or with-
17 drawal of health care unless it is consistent with the laws
18 of the State in which an advance directive is presented.

19 “(C) The provisions of this paragraph shall preempt
20 any State law to the extent such law is inconsistent with
21 such provisions. The provisions of this paragraph shall not
22 preempt any State law that provides for greater port-
23 ability, more deference to a patient’s wishes, or more lati-
24 tude in determining a patient’s wishes.”.

1 (b) MEDICAID.—Section 1902(w) of the Social Secu-
2 rity Act (42 U.S.C. 1396a(w)) is amended—

3 (1) in paragraph (1)—

4 (A) in subparagraph (B)—

5 (i) by striking “in the individual’s
6 medical record” and inserting “in a promi-
7 nent part of the individual’s current med-
8 ical record”; and

9 (ii) by inserting “and if presented by
10 the individual, to include the content of
11 such advance directive in a prominent part
12 of such record” before the semicolon;

13 (B) in subparagraph (D), by striking
14 “and” at the end;

15 (C) in subparagraph (E), by striking the
16 period and inserting “; and”; and

17 (D) by inserting after subparagraph (E)
18 the following:

19 “(F) to provide each individual with the oppor-
20 tunity to discuss issues relating to the information
21 provided to that individual pursuant to subpara-
22 graph (A) with an appropriately trained profes-
23 sional.”; and

24 (2) by adding at the end the following:

1 “(6)(A) An advance directive validly executed outside
2 of the State in which such advance directive is presented
3 by an adult individual to a provider or organization shall
4 be given the same effect by that provider or organization
5 as an advance directive validly executed under the law of
6 the State in which it is presented would be given effect.

7 “(B) Nothing in this paragraph shall be construed
8 to authorize the administration, withholding, or with-
9 drawal of health care otherwise prohibited by the laws of
10 the State in which an advance directive is presented.

11 “(C) The provisions of this paragraph shall preempt
12 any State law to the extent such law is inconsistent with
13 such provisions. The provisions of this paragraph shall not
14 preempt any State law that provides for greater port-
15 ability, more deference to a patient’s wishes, or more lati-
16 tude in determining a patient’s wishes.”.

17 (c) EFFECTIVE DATES.—

18 (1) IN GENERAL.—Subject to paragraph (2),
19 the amendments made by subsections (a) and (b)
20 shall apply to provider agreements and contracts en-
21 tered into, renewed, or extended under title XVIII of
22 the Social Security Act (42 U.S.C. 1395 et seq.),
23 and to State plans under title XIX of such Act (42
24 U.S.C. 1396 et seq.), on or after such date as the
25 Secretary of Health and Human Services specifies,

1 but in no case may such date be later than 1 year
2 after the date of the enactment of this Act.

3 (2) EXTENSION OF EFFECTIVE DATE FOR
4 STATE LAW AMENDMENT.—In the case of a State
5 plan under title XIX of the Social Security Act (42
6 U.S.C. 1396 et seq.) which the Secretary of Health
7 and Human Services determines requires State legis-
8 lation in order for the plan to meet the additional
9 requirements imposed by the amendments made by
10 subsection (b), the State plan shall not be regarded
11 as failing to comply with the requirements of such
12 title solely on the basis of its failure to meet these
13 additional requirements before the first day of the
14 first calendar quarter beginning after the close of
15 the first regular session of the State legislature that
16 begins after the date of the enactment of this Act.
17 For purposes of the previous sentence, in the case
18 of a State that has a 2-year legislative session, each
19 year of the session is considered to be a separate
20 regular session of the State legislature.

21 **SEC. 6. NATIONAL INFORMATION HOTLINE FOR END-OF-**
22 **LIFE DECISIONMAKING.**

23 The Secretary of Health and Human Services, acting
24 through the Administrator of the Health Care Financing
25 Administration, shall establish and operate directly, or by

1 grant, contract, or interagency agreement, out of funds
 2 otherwise appropriated to the Secretary, a clearinghouse
 3 and a 24-hour toll-free telephone hotline, to provide con-
 4 sumer information about advance directives, as defined in
 5 section 1866(f)(3) of the Social Security Act (42 U.S.C.
 6 1395cc(f)(3)), and end-of-life decisionmaking.

7 **SEC. 7. EVALUATION OF AND DEMONSTRATION PROJECTS**
 8 **FOR INNOVATIVE AND NEW APPROACHES TO**
 9 **END-OF-LIFE CARE FOR MEDICARE BENE-**
 10 **FICIARIES.**

11 (a) **DEFINITIONS.**—In this section:

12 (1) **MEDICARE BENEFICIARIES.**—The term
 13 “medicare beneficiaries” means individuals who are
 14 entitled to benefits under part A or eligible for bene-
 15 fits under part B of the medicare program.

16 (2) **MEDICARE PROGRAM.**—The term “medicare
 17 program” means the health care program under title
 18 XVIII of the Social Security Act (42 U.S.C. 1395 et
 19 seq.).

20 (3) **SECRETARY.**—The term “Secretary” means
 21 the Secretary of Health and Human Services.

22 (b) **EVALUATION OF EXISTING PROGRAMS.**—

23 (1) **IN GENERAL.**—The Secretary, acting
 24 through the Administrator of the Health Care Fi-
 25 nancing Administration, shall conduct ongoing eval-

uations of innovative health care programs that provide end-of-life care to medicare beneficiaries who are seriously ill or who suffer from a medical condition that is likely to be fatal.

(2) REQUIREMENTS.—Evaluations conducted under this subsection shall include the following:

(A) Evidence that the evaluated program implements practices or procedures that result in improved patient outcomes, resource utilization, or both.

(B) A definition of the population served by the program and a determination as to how accurately that population reflects the total medicare beneficiaries in the area who are in need of services offered by the program.

(C) A description of the eligibility requirements and enrollment procedures for the program.

(D) A detailed description of the services provided to medicare beneficiaries served by the program and the utilization rates for such services.

(E) A description of the structure for the provision of specific services.

1 (F) A detailed accounting of the costs of
2 providing specific services under the program.

3 (G) A description of any procedures for of-
4 fering medicare beneficiaries a choice of services
5 and how the program responds to the pref-
6 erences of the medicare beneficiaries served by
7 the program.

8 (H) An assessment of the quality of care
9 and of the outcomes for medicare beneficiaries
10 and the families of such beneficiaries served by
11 the program.

12 (I) An assessment of any ethical, cultural,
13 or legal concerns regarding the evaluated pro-
14 gram and with the replication of such program
15 in other settings.

16 (J) Identification of any changes to regula-
17 tions, or of any additional funding, that would
18 result in more efficient procedures or improved
19 outcomes, for the program.

20 (3) EXTERNAL EVALUATORS.—The Secretary
21 shall contract with 1 or more external evaluators to
22 coordinate and conduct the evaluations required
23 under this subsection and under subsection (c)(4).

24 (4) USE OF OUTCOME MEASURES AND STAND-
25 ARDS.—An evaluation conducted under this sub-

1 section and subsection (c)(4) shall use the outcome
2 standards and measures required to be developed
3 under section 2 as soon as those standards and
4 measures are available.

5 (c) DEMONSTRATION PROJECTS.—

6 (1) AUTHORITY.—The Secretary, acting
7 through the Administrator of the Health Care Fi-
8 nancing Administration, shall conduct demonstration
9 projects to develop new and innovative approaches to
10 providing end-of-life care to medicare beneficiaries
11 who are seriously ill or who suffer from a medical
12 condition that is likely to be fatal.

13 (2) APPLICATION.—Any entity seeking to con-
14 duct a demonstration project under this subsection
15 shall submit to the Secretary an application in such
16 form and manner as the Secretary may require.

17 (3) SELECTION CRITERIA.—

18 (A) IN GENERAL.—In selecting entities to
19 conduct demonstration projects under this sub-
20 section, the Secretary shall select entities that
21 will allow for demonstration projects to be con-
22 ducted in a variety of States, in an array of
23 care settings, and that reflect—

24 (i) a balance between urban and rural
25 settings;

1 (ii) cultural diversity; and

2 (iii) various modes of medical care
3 and insurance, such as fee-for-service, pre-
4 ferred provider organizations, health main-
5 tenance organizations, hospice care, home
6 care services, long-term care, and inte-
7 grated delivery systems.

8 (B) PREFERENCES.—The Secretary shall
9 give preference to applications for demonstra-
10 tion projects that—

11 (i) will serve medicare beneficiaries
12 who are dying of illnesses that are most
13 prevalent under the medicare program, in-
14 cluding cancer, heart failure, chronic ob-
15 structive respiratory disease, dementia,
16 stroke, and progressive multifactorial frail-
17 ty associated with advanced age; and

18 (ii) appear capable of sustained serv-
19 ice and broad replication at a reasonable
20 cost within commonly available organiza-
21 tional structures.

22 (4) EVALUATIONS.—Each demonstration
23 project conducted under this subsection shall be
24 evaluated at such regular intervals as the Secretary
25 determines are appropriate. An evaluation of a

1 project conducted under this subsection shall include
2 the items described in subsection (b)(2) and the fol-
3 lowing:

4 (A) A comparison of the quality of care
5 and of the outcomes for medicare beneficiaries
6 and the families of such beneficiaries served by
7 the demonstration project to the quality of care
8 and outcomes for such individuals that would
9 have resulted if care had been provided under
10 existing delivery systems.

11 (B) An analysis of how ongoing measures
12 of quality and accountability for improvement
13 and excellence could be incorporated into the
14 demonstration project.

15 (C) A comparison of the costs of the care
16 provided to medicare beneficiaries under the
17 demonstration project to the costs of that care
18 if it had been provided under the medicare pro-
19 gram.

20 (5) WAIVER AUTHORITY.—The Secretary may
21 waive compliance with any of the requirements of ti-
22 tles XI, XVIII, and XIX of the Social Security Act
23 (42 U.S.C. 1301 et seq.; 1395 et seq.; 1396 et seq.)
24 which, if applied, would prevent a demonstration

1 project carried out under this subsection from effec-
2 tively achieving the purpose of such a project.

3 (d) ANNUAL REPORTS TO CONGRESS.—

4 (1) IN GENERAL.—Beginning 1 year after the
5 date of enactment of this Act, and annually there-
6 after, the Secretary shall submit to Congress a re-
7 port on the quality of end-of-life care under the
8 medicare program, together with any suggestions for
9 legislation to improve the quality of such care under
10 that program.

11 (2) SUMMARY OF RECENT STUDIES.—A report
12 submitted under this subsection shall include a sum-
13 mary of any recent studies and advice from experts
14 in the health care field regarding the ethical, cul-
15 tural, and legal issues that may arise when attempt-
16 ing to improve the health care system to meet the
17 needs of individuals with serious and eventually fatal
18 illnesses.

19 (3) CONTINUATION OR REPLICATION OF DEM-
20 ONSTRATION PROJECTS.—Beginning 3 years after
21 the date of enactment of this Act, the report re-
22 quired under this subsection shall include rec-
23 ommendations regarding whether the demonstration
24 projects conducted under subsection (c) should be

1 continued and whether broad replication of any of
2 those projects should be initiated.

3 (e) FUNDING.—The Secretary shall provide for the
4 transfer from the Federal Hospital Insurance Trust Fund
5 established under section 1817 of the Social Security Act
6 (42 U.S.C. 1395i) of such sums as are necessary for the
7 costs of conducting evaluations under subsection (b), con-
8 ducting demonstration projects under subsection (c), and
9 preparing and submitting the annual reports required
10 under subsection (d). Amounts may be transferred under
11 the preceding sentence without regard to amounts appro-
12 priated in advance in appropriations Acts.

13 **SEC. 8. MEDICARE COVERAGE OF SELF-ADMINISTERED**
14 **MEDICATION FOR CERTAIN PATIENTS WITH**
15 **CHRONIC PAIN.**

16 (a) IN GENERAL.—Section 1861(s)(2) of the Social
17 Security Act (42 U.S.C. 1395x(s)(2)) is amended—

18 (1) in subparagraph (S), by striking “and” at
19 the end;

20 (2) in subparagraph (T), by striking the period
21 at the end and inserting “; and”; and

22 (3) by inserting after subparagraph (T) the fol-
23 lowing:

24 “(U) self-administered drugs which may be dis-
25 pensed only upon prescription and which are pre-

1 scribed for the relief of chronic pain in patients with
2 a life-threatening disease or condition;”.

3 (b) EFFECTIVE DATE.—The amendments made by
4 subsection (a) shall apply to items and services furnished
5 on or after January 1, 2000.

○

CMS Library
C2-07-13
7500 Security Blvd.
Baltimore, Maryland 21244

CMS LIBRARY



3 8095 00010424 6